



Census

2026 Census topic consultation: Submission form

This document can be used to help draft a collaborative submission or if you prefer you can email your response back to us.

On completion, please check and submit your form via:

Email: census.content@abs.gov.au

Post: 2026 Census Topic Consultation
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1. Do you give permission for the ABS to publish your submission after the consultation closes? (Select one) **(Required)**

By selecting 'Yes, publish without my name, contributors' names and email addresses':

You give permission for the ABS to publish your responses, including information in attachments, about the data you want us to collect as well as which organisation(s) you are representing. Contact name(s) for you and any other individual(s) listed in the submission and your email address will not be published.

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You give permission for the ABS to publish your responses, including information in attachments, about the data you want us to collect. The organisation(s) you are representing, contact name(s) for you and any other individual(s) listed in the submission and email address will not be published.

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No part of your submission will be published.

- Yes, publish without my name, contributors' names and email addresses
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- No

5. Has this submission been prepared in collaboration with any other individual(s) or organisation(s)?

We will not automatically send updates directly to these individuals or organisations. If they wish to receive email updates on the 2026 Census topic consultation process, they can subscribe to our [Mailing list](#).

Yes – please list name, organisation (if applicable) and email address in the section below.

No

Additional individual(s) or organisation(s)

MS Australia, [REDACTED]

Post-Polio Australia, [REDACTED]

Australian POTS Foundation, [REDACTED]

What information would you like the ABS to collect and produce statistics on?

If you have multiple topics and data needs, please complete a separate submission for each.

6. Please provide a brief summary of the information you would like the ABS to collect and produce statistics on.

The Post-Infection Disease Alliance would like the ABS to collect and produce statistics on post-infection disease as a chronic condition group. Such information could include known exposure to disease/virus types like COVID-19, Glandular Fever (Epstein Barr), Polio, measles and chickenpox. These viruses are suggested as they have all been proven to cause later consequences.

The Census is one of a number of data collection methods that would assist in building a clearer picture of post-infection disease in Australia. The COVID-19 pandemic has resulted in a large cohort of new post-infection disease patients, patients diagnosed with Long COVID. Unfortunately, data collection has been insufficient to determine the number of people living with this condition.

Long COVID is one of several conditions which have a post-infection onset. Currently, there is no national or local collection of post-infection disease data. Other common post-infection diseases include myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), multiple sclerosis (MS), postural orthostatic tachycardia syndrome (POTS) and post-polio syndrome.

Data for all post-infection diseases is inadequate. Such data could reveal new insights into disease clusters, co-morbidities and demographics of those affected. Such data will also be invaluable in preparing for the next pandemic.

The Post-Infection Disease Alliance would welcome the opportunity to provide expert advice about the appropriate questions for Census 2026.

7. What topic does this information most relate to? (Select one)

You can find more information about Census topics in our [Census dictionary](#).

- Aboriginal and Torres Strait Islander peoples
- Cultural diversity
- Health, disability, unpaid work and care
- Household and families
- Housing and homelessness
- Income, work, education and training
- Location and transport

Population, including sex and gender

Other (please specify)

8. To help us assess your submission, tell us why it is important that the ABS should collect and produce this information, including how you would use the data.

Please do not include any information which could identify you or another person.

Assessment criteria:

The ABS uses a range of criteria to assess whether it includes topics in the Census or surveys. This includes the need for the data, the ability and willingness of the public to respond and how easy it is to collect the information. Your response to this question will help with our assessment regarding the need for the data. The specific criteria we will be looking for you to address in your submission are:

- a. The topic is of current national importance.*
- b. There is a need for data at the national level, and either the local level or for small population groups.*
- c. There is likely to be a continuing need for data on the topic following the Census.*

a. The topic is of current national importance

The number of Australians living with post-infection disease is rapidly increasing due to a new cohort of post-infection disease patients: those with Long COVID. These hundreds of thousands of new patients have increased the already significant burden of post-infection disease on our health system, economy and society. [1]

Chronic diseases are the leading cause of illness, disability and death in Australia.[2] There is gathering evidence that infectious diseases are the cause of many chronic illnesses. Post-infection illness can be triggered by bacteria, viruses and parasites, or by the emergence of sub-clinical irreparable damage.

In addition to the 75% of people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) who report an infection-like episode preceding the onset of their illness,[3] recent research suggests multiple sclerosis (MS) may be caused by infection, in this case, Epstein Barr virus.[4] Similarly, postural orthostatic tachycardia Syndrome (POTS) and post-polio syndrome most commonly occur post-infection [5,6].

There is widespread acknowledgement that more research is urgently needed to fill gaps in our biomedical understanding of post-infection diseases and our ability to assess the portion of the population exposed to, and therefore carrying, a level of risk for post-infectious conditions; their etiology, pathophysiology, diagnosis, treatment and prevention.[7].

b. There is a need for data at the national level, and either the local level or for small population groups.

There is no data gathering mechanism currently in place to confirm how many Australians live with post-infection disease, and where they live. The Census is one place where data about post-infection disease should be gathered. This may include information about confirmed diagnosis (i.e. Census question 28) and effect on quality of life (i.e. is the person house or bed bound and care needs (Census questions 24-26)).

To fully understand the health, social, educational and economic impacts of post-infection diseases, we need the appropriate systems in place to gather and analyse data. The impacts of post-infection diseases are rarely considered in national, longitudinal or one-off health and wellbeing research studies.

For example, the Australian Burden of Disease Study (ABDS), conducted by the Australian Institute of Health and Welfare (AIHW), has not listed ME/CFS as a separate disease since 2003. Post-polio is also not recorded. The closest data is pre-1990 when questions were asked about 'paralysis in limbs'. This helped quantify those with a range of conditions including spinal cord injury, post-polio conditions and nerve damage.

Data for small population groups, like those living with post-polio syndrome, can assist in the development of targeted programs that address health literacy. In addition, data can assist with understanding health system costs and patient out-of-pocket costs assessment. Such data could be captured with a question like "What is the annual out of pocket cost for your most debilitating chronic condition, if you have one?"

c. There is likely to be a continuing need for data on the topic following the Census.

While COVID-19 is a new illness, post-acute sequelae of SARS-CoV-2 infection, or Long COVID, is most likely the latest post-infection illness in a long history. The acute symptoms of viral illnesses like COVID-19, Epstein Barr virus and polio, can be very different. However, the lingering illness following each infection can be quite similar, both in symptomatology and underlying biology, particularly in the cases of ME/CFS and Long COVID.[8],[9]

Current estimates suggest 5% to 10% of people who have had COVID-19 will still be experiencing symptoms after 12 weeks [10], and can therefore be classified as having Long COVID.[11] Australia has had an estimated cumulative 11.2 million COVID-19 cases to the end of April 2023, although some of these will be reinfection.[12] This means between 500,000 and 1 million people could be living with Long COVID, although our high vaccination rate would suggest the lower end of this range, as vaccinations have been proven to lower the risk of Long COVID [13]. The number of people with Long COVID will continue to grow as COVID becomes endemic.

COVID-19 only adds to the number of other viruses, bacteria and parasites in the community that can cause post-infection illness: these estimates don't include the many hundreds of thousands of Australians already living with post-infection disease. We need better data to accurately know how many Australians this is, where they live, and the effect post-infection illness is having on their lives.

Post-infection diseases also have a profound impact on carers, particularly those who provide support to the 25% of patients who are house or bed-bound. Emerge Australia's 2019 Health and Wellbeing Survey reported 90% of carers were financially unsupported in their role as

carer.[14] This causes inter-generational financial burden in the case of parents, and compounds financial stress for domestic partners.[14]

Up-to-date statistics are essential to enable Australia's health and social care systems to support people with post-infection diseases. This data could be used to inform a number of policy positions including:

- Economic impact
- Disability support
- Health funding
- Research funding.

References:

1. House of Representatives, Standing Committee on Health, Aged Care and Sport (2023). 'Sick and tired: Casting a long shadow. Inquiry into Long COVID and Repeated COVID Infections'. Parliament of Australia, Canberra. Available at: https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/RB000006/toc_pdf/SickandtiredCastingalongshadow.pdf.
2. Australian Institute of Health and Welfare. (2022). 'Health conditions, disability & deaths' Australian Government. Available at: <https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths> (accessed 2 November 2022).
3. H. Naess, et al. (2010). 'Postinfectious and chronic fatigue syndromes: clinical experience from a tertiary-referral centre in Norway' *Vivo*, 24:2.
4. Bjornevik, K, Cortese, M, Healy, B, et al. (2022). "Longitudinal analysis reveals high prevalence of Epstein-Barr virus associated with multiple sclerosis" *Science* 375:6578. pp 296-301.
5. Benarroch, E (2012). 'Postural Tachycardia Syndrome: A Heterogeneous and Multifactorial Disorder'. *Mayo Clin Proc*, Dec; 87(12): 1214–1225.
6. Queensland Health (2001). 'The Late Effects of Polio: Information for General Practitioners'. Available at: <https://www.polionsw.org.au/wp-content/uploads/2013/07/The-Late-Effects-of-Polio-Information-for-General-Practitioners.pdf>.
7. Choutka, J., Jansari, V., Hornig, M. et al. (2022) 'Unexplained post-acute infection syndromes.' *Nat Med* 28, 911–923. <https://doi.org/10.1038/s41591-022-01810-6>.
8. Komaroff, A. and Bateman, L. (2021). 'Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?' *Frontiers in Medicine*, 7.

9. Komaroff, L. & Lipkin, W. (2021). 'Insights from myalgic encephalomyelitis/chronic fatigue syndrome may help unravel the pathogenesis of postacute COVID-19 syndrome' Trends in molecular medicine, 27:9.
10. Australian Institute of Health and Welfare (2022). 'Long COVID in Australia – a review of the literature'. Australian Government, Canberra. Available at: <https://www.aihw.gov.au/getmedia/9592f439-9b96-4589-a55d-6b04e262e5e1/aihw-phe-318.pdf.aspx?inline=true>.
11. Soriano, J., et al. (2021). 'A clinical case definition of postCOVID-19 condition by a Delphi consensus' The Lancet Infectious Diseases. Available at: https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1.
12. World Health Organisation (2023). 'WHO Health Emergency Dashboard . Global . Australia' Available at: <https://covid19.who.int/region/wpro/country/au> [accessed 27/4/23].
13. Byambasuren, O, et al. (2023). 'Effect of covid-19 vaccination on long covid: systematic review'. BMJ Medicine, ;2:e000385. doi:10.1136/bmjmed-2022-000385.
14. Emerge Australia. 'Health and Wellbeing Survey 2019'. Available at <https://www.emerge.org.au/health-and-wellbeing-survey-2019>.

9. For what purpose(s) will you use the data? (Select all that apply)

- Resource allocation for programs and policies
- Planning, development, monitoring and evaluation related to programs, policies and service delivery
- Research
- Journalism/media
- Other (please specify)

10. What is the smallest area or geography required to effectively use this data? (Select one)

Common geographies or area boundaries:

- *Mesh Block (Residential block/rural area)*
- *Statistical Area Level 1 (Neighbourhood/rural district)*
- *Statistical Area Level 2 (Suburb or locality)*
- *Statistical Area Level 3 (Part of region)*
- *Statistical Area Level 4 (Region)*
- *Greater Capital City Statistical Areas (Capital city broad regions)*
- *Significant Urban Areas (Large urbanised areas)*
- *Urban Centres and Localities (Cities and towns)*
- *Indigenous Locations (Aboriginal and Torres Strait Islander communities)*
- *Remoteness Areas (Remoteness Classification)*
- *Local Government Areas*
- *State Electoral Divisions*
- *Commonwealth Electoral Divisions*

More information is available on the [Census geography glossary](#) page.

- National
- State/territory
- Statistical Area Level 2 (suburb or locality)
- Statistical Area Level 1 (neighbourhood/rural district)
- Local Government Area
- Don't know
- Other (please specify)

Additional information

11. Would you like to tell us anything else about your submission?

Please do not include any information which could identify you or another person.

You can also attach documentation to support your submission. Please make sure your file is under 25MB.

Please note if you have provided consent for the ABS to publish your submitted information, this includes information provided in attachments.

Thank you...

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